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ABSTRACT

The paper designed to evaluate independent living for handicapped persons as a social movement, analyze the movement's expression in disability services, and consider the movement's implications for disability research. An initial section recounts the movement's constituency, origins, legislative history, and its relationship to such social movements as civil rights, consumerism, self-help, demedicalization, and deinstitutionalization. Three major assumptions (consumer sovereignty, self reliance, and political and economic rights) of the movement are seen to be central to the movement's ideology regarding free market theory, and the political theory of democratic pluralism. Specific disability services (such as advocacy, attendant care, and peer counseling services) are pointed out as illustrative of the movement's philosophy. The final section proposes an analytic paradigm for independent living which sees that the problem does not reside in the individual but often in the dependency inducing features of the rehabilitation paradigm. Future considerations regarding the role of able bodied persons and pending legislation are addressed. (CL)

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THE MOVEMENT FOR INDEPENDENT LIVING: ORIGINS, IDEOLOGY, AND IMPLICATIONS FOR DISABILITY RESEARCH

by

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ABSTRACT

The purpose of this paper is three-fold: (1) to evaluate independent living as a social movement, (2) to analyze the movement's expression in disability services, and (3) to consider the movement's implications for disability research. In keeping with this three-fold purpose, the paper analyzes in depth the movement's constituency, origins, legislative history, and its relationship to allied social movements such as civil rights, consumerism, self-help, demedicalization, and deinstitutionalization. This analysis enables us to identify the movement's values and ideological assumptions. The paper argues that independent living is more than a social movement but also an analytic paradigm that makes certain assumptions about the etiology of dependency and its amelioration. The independent living paradigm is contrasted with the rehabilitation paradigm that has dominated disability research. The paper analyzes how the shift from the rehabilitation paradigm to the independent living paradigm is likely to affect the future of disability research.

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THE MOVEMENT FOR INDEPENDENT LIVING: ORIGINS, IDEOLOGY, AND IMPLICATIONS FOR DISABILITY RESEARCH

> A significant social movement becomes possible when there is a revision in the manner in which a substantial group of people looking at some misfortune, see it no longer as a misfortune warranting charitable consideration but as an injustice which is intolerable in society. (Turner, 1969: 321)

I

Introduction

Future historians of American social policy will look back to 1973 as a year which separates one epoch of disability policy from another. That year Congress passed a new Rehabilitation Act which set into motion a whole set of new initiatives affecting the nation's disabled population, particularly its most severely physically disabled citizens.

The most visible feature of the 1973 Rehabilitation Act is Section 504, a one-sentence statement prohibiting discrimination against "qualified handicapped" individuals "under any program or activity receiving Federal financial assistance." Because of this section's far-reaching implications, the 1973 Rehabilitation Act has sometimes been dubbed "the Civil Rights Act of the Handicapped."

The 1973 Act cannot be fully understood apart from an emerging social movement---the movement for independent living. Sparked with a high degree

of indigenous leadership from among the disabled population, the movement seeks a better quality of life for disabled persons. Its chief focus has been the most severely disabled who have traditionally been confined to long-term care institutions. In some quarters, independent living has become a code word for deinstitutionalization and the establishment of community based alternatives.

The movement for independent living is more than a grass roots effort on the part of disabled persons to acquire new rights and entitlements. The movement is also reshaping the thinking of disability professionals and researchers. It has spawned new service delivery models and has encouraged new research directions.

The purpose of this monograph is three-fold. First is to consider independent living as a social movement and to evaluate the movement in terms of its constituency, origins, legislative background, relationship to other social movements, and its ideological commitments. Second is to analyze how the movement has come to expression in disability services. And third is to consider the implications of the movement for disability research. This paper will roughly follow the order indicated by this three-fold purpose. Each discussion sets the stage for the next.

Independent living has not always been recognized as a social movement. My purpose here is not to determine whether independent living meets every test of being a social movement.[1] However, by considering independent living as a social movement we acquire an analytic devise by which we can better

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[1]An extensive literature has developed exploring and defining the nature of social movements (Ash, 1972; Cameron, 1966; Gerlach and Hine, 1972 and 1973; Gerschwender, 1968; Gusfield, 1969; Herbele, 1951; Hopper, 1950; Howard, 1974; McLaughlin, 1967; Meadows, 1943; Obuscall, 1973; Toch, 1965; Turner, 1969 and 1970; Warren, 1977; Wilkinson, 1971; Wilson, 1972; Zald and Ash, 1966; and Zygmunt, 1972).

identify those values, goals, and assumptions that give this social phenomenon---we call independent living---meaning and direction. By understanding independent living as a social movement we can also better analyze the implications of independent living for disability policy and research.

II

The Prevalence of Disability and the Movement's Constituency

The movement for independent living has always counted the "severely disabled" as its primary target group or constituency. But who are the severely disabled? How many are there?

Results from National Survey Data

One common method used to define and measure severe disability is the inability to work or to carry on one's major activity. Based on results from its 1974 Health Interview Survey (HIS), the National Center for Health Statistics (NCHS) estimates that 3.3 percent or 6.8 million of the nation's population are unable to carry on their major activity. See Table 1. Going across different age groups, about 0.2 percent of all children[2], 2.6 percent of all working age adults, and 17.1 percent of all the elderly[3] are unable to carry on their major activity.

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[2]For children the inability to carry on one's major activity would mean the inability to play or go to school.

[3]It is unclear what "limitations in major activity" mean for the elderly. The Health Interview Survey evaluates the elderly in the same manner as working age adults: whether or not a person is limited in their ability to work. (For the definitions of disability used by HIS see National Center for Health Statistics (1976: 35-37).) Asking an elderly person whether they are able to work seems increasingly inappropriate the more a person is removed in age from participating in the labor force and when the usual kind of work remains unspecified. Moreover, an elderly person's ability to work remains untested in a society that demands mandatory retirement.

Table 1

Percentage Distribution of Total Population[a] by Degree of Activity Limitation and Age Group
United States, 1974[b]

Degree of Activity Limitation	Total Population (N=207.3 million)	Age Group		
		Under 17 yrs. (N=63.0 million)	17-64 yrs. (N=123.6 million)	Over 64 yrs. (N=20.7 million)
With no activity limitation	85.9%	96.3%	85.9%	54.1%
With activity limitation	14.1	3.7	14.1	45.9
Limited but not in major activity	3.5	1.8	3.9	6.6
Limited in amount or kind of major activity	7.3	1.7	7.6	22.1
Unable to carry on major activity	3.3	0.2	2.6	17.1
Totals	100.0	100.0	100.0	100.0

Source: National Center for Health Statistics (1976:11, Table 1).

[a]Noninstitutionalized civilian population.

[b]As estimated by the Health Interview Survey, 1974.

If we expand the definition of severe disability to include those who are able to carry on their major activity but are limited in amount or kind of activity, the number of severely disabled persons increases appreciably. Based on the same Health Interview Survey (see Table 1 again), combining the two most activity restricted groups, 10.6 percent or 22.0 million of the nation's population would be classified as severely disabled.

By focusing on limitations in a person's major activity, the Health Interview Survey uses a "social role" definition of disability. This definition points up a problem that has been of interest to those involved in the movement for independent living. The social role definintion of disability has a large environmental component: limitations in one's major activity depend in large part upon the presence or absence of environmental barriers. These barriers---whether they be inaccessible places of employment or inadequate home care services---and not the physical impairment, may determine whether a person is limited in his/her major activity.

A less environmentally biased definition of severe disability is the physical functioning definition of disability. This definition focuses on the ability to move certain limbs or the ability to be independent in personal hygiene and mobility.[4] Needing help with personal care is generally considered the most restrictive level of physical functioning in large national surveys and is sometimes used as an alternative definition of severe physical disability. As noted in Table 2, about 1.2 percent of the child age population,[5]

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[4]Even the performance of these activities can be limited by environmental constraints.

[5]Since very young children require help with personal care on a regular basis, the 1972 Ohio State Survey (cited in Table 2) considered only children who required extra help with personal care because of a physical, mental, or emotional problem.

Table 2

Number and Percentage Distribution of Population[a] Needing Some Help From Another Person for Personal Care and Mobility by Age Group as Estimated by Various National Surveys United States, 1966-68, 1972

Survey and Age Group	Needs Help From Another Person With Personal Care		Needs Help From Another Person With Mobility[b]	
	Number (thousands)	Percent[c]	Number (thousands)	Percent[c]
Social Security Survey, 1966	1,259			
18-64 yrs.	1,259	1.2%	1,851	1.8%
Social Security Survey, 1972*				
20-64 yrs.	1,534	1.4	2,619	2.4
20-34 yrs.	217	0.5	597	1.4
35-44 yrs.	209	1.0	414	1.9
45-54 yrs.	391	1.7	581	2.5
55-64 yrs.	716	3.8	1,028	5.4
Ohio State Survey, 1972				
Under 18 yrs.	858[d]	1.2	na	na
18-44 yrs.	372[d]	0.5	442[d]	0.6
45-54 yrs.	na	1.4	na	2.0
55-64 yrs.	na	2.7	na	5.2
45-64 yrs.	837[d]	2.0	1,612[d]	3.8
18-64 yrs.	1,254[d]	1.1	2,149[d]	1.8
65-74 yrs.	na	3.0	na	8.5
Over 74 yrs.	na	9.1	na	16.7
Over 64 yrs.	1,046[d]	5.2	2,298[d]	11.5
All adults	2,510[d]	1.8	4,934[d]	3.5
Health Interview Survey, 1966-68				
Over 55 yrs.	1,747	4.9	na	na
55-64 yrs.	363	2.1	na	na
Over 65 yrs.	1,385	7.7	na	na
65-74 yrs.	499	4.4	na	na
Over 75 yrs.	886	13.4	na	na

Table 2
(continued)

Survey and Age Group	Needs Help From Another Person With Personal Care		Needs Help From Another Person With Mobility[b]	
	Number (thousands)	Percent[c]	Number (thousands)	Percent[c]
Health Interview Survey, 1972				
Under 17 yrs.	na	na	81	0.1
17-44 yrs.	na	na	229	0.3
45-64 yrs.	na	na	663	1.6
17-64 yrs.	na	na	892	0.7
Over 64 yrs.	na	na	1,374	6.9
All adults	na	na	2,226	1.6
All ages	na	na	2,348	1.1

Sources: Haber (1970:19, Table 1), Burdette (1972:13, Table 1; 31, Table 17), Posner (1977:12-13, Table 1), Nagi (1973:IV-16, Table IV-8; 1975:39, Table 9, 1975:39, Table 9), Nagi and Luken (1975:10, Table 5), and National Center for Health Statistics (1972:3&15, Table 1; 1974:16, Table 2).

[a] Noninstitutionalized civilian population.

[b] In the Social Security Survey, those requiring help with mobility overlapped with those requiring help with personal care, i.e., the person requiring help with both activities would be counted twice. In the Ohio State University Survey, those requiring help with mobility did not overlap with those requiring help with personal care, i.e., these two groups are mutually exclusive. In the Ohio State University Survey, those needing help with personal care were considered more dependent than those needing help with mobility (Nagi, 1973:IV-13). Since the Ohio State University Survey classified people into their most dependent category, it is possible to compare the two surveys in terms of needing help for personal care, but not mobility.

[c] Percent of each age group.

[d] Based on extrapolations of Ohio State University Survey data to Census data. Since the age distribution in the Ohio State Survey was slightly different than the age distribution for the nation as a whole, the numbers of each age group are not additive.

about 1.2 percent of the working age population, and about 7.7 percent of the elderly population need some assistance from another person with personal care. If these percentages were applied to the current age distribution, about 3.6 million would need some assistance from another person with their personal care.

The percentage of the population needing help with mobility varies from about 2.0 percent of the working age population to about 7.0 percent of the elderly population. None of the five surveys reviewed here[6] report data on childhood mobility.

In pinpointing the movement's constituency from these national data, two additional factors need to be considered. First, those who are dependent in personal care and those who are dependent in mobility are overlapping groups; the statistics are not additive. Second, national survey data do not provide any indication as to how much assistance an individual or group needs in personal care or mobility. Since the movement for independent living is primarily concerned about persons who need substantial assistance with personal care or mobility, these national statistics suggest that the movement is focused on a relatively small percentage of the nation's population.

Core Constituency

However, the movement's core constituency is even more limited than that suggested by these national data. The movement has concentrated its energies on a relatively few major disability groups: those with spinal cord injury, muscular dystrophy, cerebral palsy, multiple sclerosis, and

[6]The five national surveys reviewed here are listed in Table 2.

post-polio disablement. These five groups indeed comprise a very small but not insignificant portion of the nation's population.

Moreover, the movement for independent living has concentrated its energies on a selected age group: the older adolescent and younger working age adult. The emphasis on this narrow age range is, in part, a function of the disabling conditions mentioned above. For example, spinal cord injury is most common among males during their late teens and early twenties when they are most likely to participate in disability-prone activities. Multiple sclerosis generally becomes evident during one's twenties. Cerebral palsy and muscular dystrophy are developmental disabilities and thus are already evident during a person's childhood years. Those with a post-polio disablement are the senior members of the movement.

The emphasis on the younger adult is also a function of the communities where the movement has taken root. The movement for independent living has been most active in large academic communities containing critical masses of university-aged persons. Free from some of the more demanding familial and economic responsibilities, this age group is often better able to organize around major social issues.

Notably absent from the movement's constituency are older persons with severe physical impairments resulting from stroke or other degenerative conditions. While the movement's philosophy may have direct relevance to older disabled persons, the movement has focused its concern elsewhere. The movement's present age bias is one that cannot last indefinitely. Medical science is not only enabling severely disabled persons to survive initial trauma but is also enabling severely disabled persons to live longer.

Thus, as the movement's initial adherents grow older we can expect the movement to enlarge its present age focus.[7]

Disability Professionals and Special Interest Organizations

There is another part of the movement's constituency that deserves mention here: the disability professionals and special interest organizations. The disability professionals include physicians in physical medicine and rehabilitation, physical therapists, occupational therapists, nurses, rehabilitation counselors, and disability researchers. The commitment of these professionals to the movement varies widely and generalizations cannot be made except that the movement is increasing its number of adherents. The special interest groups include organizations such as the National Paraplegia Foundation, the Easter Seal Society, and various professional associations. Again, the commitment of these organizations varies widely from chapter to chapter.

In defining the movement's constituency one should not overlook the overlap between disabled "consumers" and disability professionals. Many disabled persons are themselves disability professionals. The participation of able-bodied professionals in the movement can to some degree be explained by the influence and the consciousness raising impact of their disabled professional peers.

The movement's strength comes, in part, from linking the interests of its primary disability groups with the interests of other disability

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[7]Also absent from the movement's constituency and leadership are racial minorities. Disability statistics indicate that racial minorities have a higher prevalence of disability than do their white counterparts (DeJong, 1977a: 53; U.S. Bureau of the Census, 1973b: 239, Table 52). The absence of racial minorities deserves special analysis. Given the similarities between the civil rights movement, the black movement, and the movement for independent living (see pages 20-22), one would think that the movement for independent living would attract disabled persons from racial minorities.

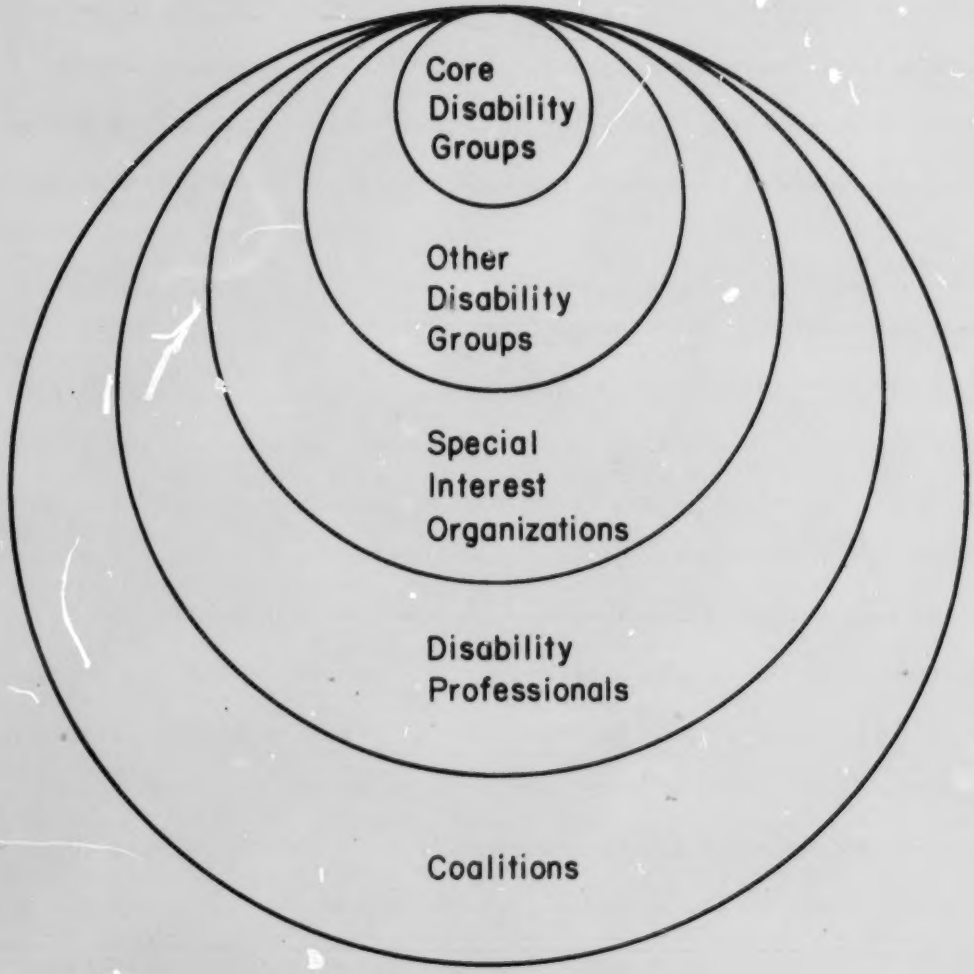

Figure 1. The Movement for Independent Living's Constituency

groups, especially on issues of common concern. The issue of architectural barriers, for example, is one that unites other mobility impaired groups, even though its greatest effect is on the core disability groups represented in the movement for independent living. Coalition building through organizations such as the American Coalition of Citizens with Disabilities (ACCD) has enabled the movement to enlarge its constituency around specific issues.

Difficult to Define

We may conclude that the movement's constituency is hard to define. National survey data enables us to identify that portion of the population most likely to come within the scope of the movement's concern. While we can identify a core constituency, there are many other interested parties---professionals and special interest groups---who have come to recognize the movement and have joined forces to one degree or another. See Figure 1. Moreover, common interests with other disability groups enables the movement to extend its influence beyond the boundaries of the core disability groups.

The movement's constituency is defined by more than who participates, but also by what it advocates. The movement's constituency, in some respects, extends to others who do not actively participate but who nonetheless come under its consciousness-raising spell and thus become informal advocates of the movement's philosophy and ideology.[8] In subsequent sections we will be exploring in greater depth the movement's philosophical and ideological commitments.

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[8]The problem of constituency definition is similar to that in the women's movement. The constituency of the women's movement is not limited to its most active participants but in a sense also includes women and men who have come to accept the movement's values and can be expected to vote and accept a life style in keeping with those values.

III

Origins and Legislative Background

It is difficult to point to an exact time when, or a place where, the movement for independent living began. The movement has sprung from two main sources. The first source is the efforts of disabled persons to seek a more fulfilling life in an able-bodied world. The second source is the efforts of rehabilitation professionals to reach disabled persons for whom a vocational goal was, until recently, unthinkable. While the efforts of both groups often converge on specific legislation, their interests and origins are sufficiently different to warrant separate consideration.

Indigenous Origins

The disabled students program at the University of Illinois at Champaign-Urbana was among the first to facilitate community living for persons with severe physical disabilities. In 1962, four severely disabled students were transferred from a nursing home isolated from campus to a modified home closer to campus. The disabled students program has since emerged as a significant self-help effort and has helped to make the University of Illinois one of the most architecturally accessible institutions of its kind.

It was not until the early 1970's that the movement gained greater visibility and momentum with the creation of the Center for Independent Living (CIL) in Berkeley, California. The Berkeley CIL incorporated itself in 1972 as a self-help group to be managed primarily by persons who were themselves disabled. The center provides a wide range of related services such as peer counseling, advocacy services, van transportation, training in

independent living skills, attendant care referral, health maintenance, housing referral, wheelchair repair, and others (Brown, 1978: 24; Stoddard, 1978: 2-3). Unlike other centers that have since emerged, the Berkeley CIL has no residential program. The Berkeley CIL serves persons with a greater variety of disabling conditions than do many other existing centers.[9]

On the East Coast, the Boston Center for Independent Living (BCIL) began its activities in 1974. BCIL emphasizes transitional housing and attendant care services (Corcoran, et al., 1977). Similar centers and organizations have sprung up in Houston, Columbus, Ann Arbor, and in other locations. New centers seem to emerge almost weekly. Each center offers its own unique blend of advocacy and consumer services. The various centers have given the movement for independent living both an organizational focus and a vehicle for realizing some of the movement's more important goals.

The movement's organizational efforts have not been limited to centers for independent living. Allied organizations such as the American Coalition of Citizens with Disabilities (ACCD), mentioned earlier, have been instrumental in monitoring federal legislation affecting disabled persons. The ACCD also helped to organize the coast-to-coast demonstrations that goaded the U.S. Department of Health, Education and Welfare (HEW) to promulgate regulations implementing Section 504 of the 1973 Rehabilitation Act.

Professional Origins

Developing concurrently with the organizational initiatives of disabled persons were the efforts of rehabilitation professionals in the formulation of national legislation.

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[9]Since 1974, nineteen independent living programs have surfaced in California alone.

In 1959, H.R. 361 was introduced[10] containing language that would extend independent living services to individuals for whom employment was not an obtainable objective (Urban Institute, 1975: 4-10; Parsons and Counts, 1978: 1-6). That attempt failed and in 1961 a new bill, written largely by the National Rehabilitation Association, was introduced. The new bill contained a separate title on independent living services. That bill also failed.

If adopted, the 1961 bill would have authorized $15 million in the first year and $25 million in the second year for independent living rehabilitation services. The new title was to be administered by state vocational rehabilitation agencies that were to enter into cooperative arrangements with other state agencies providing income assistance and health-related services. Administration opposition to the bill contributed to its demise. The reasons for Administration opposition are unclear but anecdotal evidence has it that the U.S. Department of Health, Education and Welfare (HEW) was unable to determine which of its competing agencies should administer the new title.[11]

The 1973 Rehabilitation Act

In 1972, Congress passed H.R. 8395 amending the Vocational Rehabilitation Act to provide independent living services to those individuals "for whom a vocational goal is not possible or feasible." The bill was twice vetoed by the President on the grounds that it "would divert the (vocational

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[10]Later reintroduced as H.R. 5416.

[11]A weak backdoor version of an independent living rehabilitation services program was introduced in the 1956 Amendments to the Vocational Rehabilitation Act. The Amendments provided for an "extended evaluation" of severely disabled applicants whose suitability for vocational rehabilitation services could not be immediately determined. While awaiting final eligibility determination, these individuals could receive support services that would enhance their chances for vocational rehabilitation.

rehabilitation) program from its basic vocational objectives" toward more ill-defined medical and welfare goals (Urban Institute, 1975: 9-10).

To break the stalemate between Congress and the Administration, a compromise was reached and the 1973 Rehabilitation Act came into being. Congress agreed not to insert authorizations for independent living programs and in exchange the Administration agreed to conduct a comprehensive study on the needs of severely handicapped individuals.[12] While it was the intent of the Administration to dislodge the momentum toward an independent living program, the needs study has, since its completion in 1975 by the Urban Institute, proved to be a valuable document and resource to independent living advocates.

The 1973 Rehabilitation Act did contain other break-throughs important to those in the movement for independent living. First, it mandated that those who were most severely handicapped were to receive first priority for services under the Act. Second, Title V extended new statutory rights to handicapped persons. Sections 501 and 503 mandated affirmative action programs for the employment of disabled persons within the federal government and by organizations contracting with the federal government. Section 502 created the Architectural and Transportation Compliance Board. And Section 504 banned discrimination on the basis of handicap in any program or activity receiving or benefiting from federal financial assistance. Together, these four sections comprising Title V have sometimes been referred to as the civil rights title of the Act.

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[12]The study was authorized under Section 130 of the Act (P.L. 93-112).

Differing Views of Independent Living

A couple of things need to be said about the concept of independent living services as advocated by vocational rehabilitation professionals.

First, the concept of independent living rehabilitation has changed since it was originally introduced to Congress almost two decades ago. Since then, medical and rehabilitation technology has advanced significantly. Those who would have been targeted for independent living rehabilitation services 15 years ago are now routinely prepared for gainful employment by state vocational rehabilitation agencies.

Second, vocational rehabilitation professionals, as reflected in the legislation reviewed here, have a different conception of independent living than do their consumer counterparts in the movement for independent living. For many vocational rehabilitation professionals, independent living services are for those for whom a vocational goal is thought to be impossible. Independent living is seen as an alternative to the vocational goal---thus, the term "independent living rehabilitation" as distinct from "vocational rehabilitation". Independent living rehabilitation refers to those medical and social services that enable a disabled person to live in the community short of being gainfully employed. From this perspective, independent living and rehabilitation are seen as competing policy goals. Throughout the history of the legislative debate on independent living, there has been the fear that independent living would dilute the specificity of the vocational outcome. Some professionals feared that independent living services would result in the same charges of nonaccountability often levied against more ill-defined

social services such as those administered under Title XX of the Social Security Act.[13]

Others in the movement for independent living, whose involvement do not originate in the vocational rehabilitation tradition, reject the conception of independent living and employment as competing policy goals. To them, such a conception is potentially sinister: it implicitly places an arbitrary upper limit to the goals a disabled person might set for him or herself. No upper limit should be set. Limits tend to be self-fulfilling. Instead, the vocational objectives should be seen as an integral part of the independent living goal, not as a competing goal.

Other Legislation

The movement for independent living has also been shaped by (or has shaped) legislation outside the vocational rehabilitation tradition. This legislation includes:

- Education for All Handicapped Children Act of 1975 (P.L. 94-142).
- Developmentally Disabled Assistance and Bill of Rights Act (P.L. 94-103).
- National Housing Act Amendments of 1975 (P.L. 94-173).[14]

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[13]It is interesting to note that when earlier versions of the 1973 Rehabilitation Act were being rejected by the Nixon Administration, the same administration was preoccupied with the explosion of social service expenditures under Title IVA of the Social Security Act, the precursor to Title XX. In his second veto message, the President condemned the bill because it would redirect vocational rehabilitation toward "welfare goals." The choice of words here may well have been influenced by the Administration's preoccupation with social service expenditures.

[14]The responsibility for implementing Title I of the Act has been delegated to the well-publicized Office of Independent Living for the Disabled within the Department of Housing and Urban Development.

- Architectural Barriers Act of 1968 (P.L. 90-480 and as amended in P.L. 94-541).
- Federal-Aid Highway Act of 1973 (P.L. 93-87 and as amended in P.L. 93-643).
- Department of Transportation Appropriations Act of 1975 (P.L. 93-391).

These acts have opened up educational opportunities for disabled children and have helped to make housing, public buildings, highway facilities, and public transportation more barrier free (Parsons and Counts, 1978: 8).

Future Legislation

The legislative goals of the movement for independent living have centered on issues such as discrimination, architectural barriers, and specialized services. Much of the enabling legislation is in place. The legislative agenda of the movement is by no means complete. One priority for the movement is the careful monitoring of governmental agencies to assure full compliance with the legislation's stated purposes. A second priority is the advocacy and development of new legislation particularly in the funding of independent living support services and the removal of employment disincentives within various health and welfare benefit programs.[15, 16]

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[15]It is this author's contention that the work disincentives, caused by the sudden loss of needed health and welfare benefits when a disabled person becomes gainfully employed, are among the most important determinants of independent outcomes.

[16]See also discussion on pending legislation, pages 58-59.

IV

Relation to Other Social Movements

The movement for independent living has flourished at a time when several other complementary social movements have also developed. These movements include:

- civil rights
- consumerism
- self-help
- demedicalization/self-care
- deinstitutionalization/normalization/mainstreaming

While these movements share common values and assumptions, each arises from a somewhat different source in response to different social problems. Each has influenced the movement for independent living to one degree or another. The origins and ideology of the movement for independent living cannot be fully appreciated without noting the contributions of other social movements. My strategy here is to evaluate the nature and influence of each movement before considering their common ideological assumptions and the meaning of these movements for disability services and research.

Civil Rights

The civil rights movement of the 1960's has had an impact far beyond the racial minorities it sought to benefit. The movement made other disadvantaged groups aware of their rights and aware of how their rights were being denied. During the initial stages, the movement was mainly concerned with civil rights as opposed to benefit rights. Civil rights include the right to vote, to hold elective office, to be tried by a jury of one's peers,

and so forth. Benefit rights include the entitlement to income and medical assistance benefits, educational benefits, and other entitlements. The benefit rights issue was taken up later in the civil rights movement by the Poor Peoples' Campaign and by spin-offs such as the National Welfare Rights Organization.

The concern for both civil rights and benefits rights has spilled over to other vulnerable groups. In the area of mental health, patients have, in some instances, acquired the right to refuse treatment and to expect certain levels of care. In the area of child welfare, children have acquired new procedural rights that are slowly replacing the best-interest-of-the-child rule as the legal standard for adjudicating abuse and delinquincy cases. Moreover, children are receiving rights to treatment and education under special education statutes.

The movement for independent living has been similarly concerned with both civil and benefit rights. The movement's interest in civil rights is reflected in Title V of the 1973 Rehabilitation Act prohibiting various forms of discrimination particularly in the area of employment. However, the concern for civil rights has not stopped there. Persons with severe mobility impairments are insisting that architectural and other environmental barriers in effect deprive them of their civil rights when these barriers prevent them from participating in the political life of the community. In like fashion, disabled persons have become aware that their benefit rights are prerequisites for living in a community setting. Without income assistance benefits or attendant care benefits, many disabled persons would be involuntarily confined to a long-term care facility.

The civil rights movement has not only had an effect on the securing of certain rights but also on the manner in which those rights have been secured. When traditional legal channels have been exhausted, disabled persons have learned to employ other techniques of social protest such as demonstrations and sit-ins.

The black movement that eventually grew out of the civil rights movement has had its own effect on the movement for independent living. According to the critique offered by the civil rights movement, racial discrimination was an American anomaly that could largely be removed through the enactment of new legal protections. The black movement saw the issue as one of racism that was central to the definition of white America and beyond the scope of simple legal remedies. The movement for independent living has come to recognize that prejudice against disability is rooted in our culture's attitudes about youth and beauty, and in the able-bodied person's fear of vulnerability to physical disability. The black movement has inspired the movement for independent living to search more deeply for the sources of attitudes and behaviors toward persons with disabilities.

Consumerism

The parameters of the consumer movement are hard to define. It is a movement that affects nearly all social classes and groups. The movement is most personified by Ralph Nader but also includes public interest lawyers representing various disadvantaged groups. The movement embraces both the person who devotedly reads Consumer Reports and the person who campaigns for new consumer protection legislation. Because the parameters of the movement are hard to define, a more profitable venture here would be to

briefly evaluate the movement in terms of its ideology---consumerism, and in terms of its expression in disability policy.

Basic to consumerism is a distrust of seller or service provider. It is up to the consumer to become informed about product reliability or service adequacy. Consumer sovereignty has always been the hallmark of free market economic theory. In practice, however, it is often the professional who has been sovereign.

With the rise of consumer sovereignty, professional dominance in disability policy and rehabilitation is being challenged. In vocational rehabilitation, for example, the professional counselor does not necessarily have the final word in case planning as he/she once did. Instead, the Rehabilitation Act of 1973 provides for an "individualized written rehabilitation plan" (IWRP)[17] to be drawn up jointly by client and counselor. Outside vocational rehabilitation, the movement for independent living has spawned new advocacy centers to advise disabled persons of their legal rights and benefits. With the awareness generated by the movement for independent living, the disabled person with several years of disability experience is often better informed about governmental benefits and regulations than his/her professional counterpart in the human services system.

Self-Help

The self-help movement embraces a large variety of groups: from the Female Improvement Society to Alcoholics Anonymous (Withorn, 1977: 221). There now appears to be a self-help group for almost every conceivable human

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[17]See Sections 101 (a)(9) and 102 of the Rehabilitation Act of 1973 (P.L. 93-112).

condition or problem---alcoholism, drugs, gambling, death, homosexuality, child abuse, women's health, old age, sex, neighborhood crime, cigarette smoking, child birth, and of prime interest here, physical disability (Back and Taylor, 1976; Hurwitz, 1976; Levy, 1976; Reisman, 1976; Withorn, 1977). Self-help organizations view themselves as mutual aid groups that serve as adjuncts or as valid alternatives to established human service agencies (Durman, 1976; Levin, 1976; Sidel and Sidel, 1976; Tax, 1976; Withorn, 1977). Self-Help groups usually address problems and needs not dealt with by other institutions in society.

Among disabled persons, centers for independent living have become the primary self-help unit. The various centers seek to serve both as an adjunct to the present human service system and as an alternative service provider. As an adjunct to the system, the centers at times serve as conduits for funding human services such as attendant care. As an alternative to the system, the centers may provide peer counseling and advocacy services not provided by mainline human service organizations.

The self-help movement is fueled by the same distrust of professionally dominated services mentioned in our discussion on consumerism. Self-help organizations are intended to give people the opportunity to exercise control over their own lives and the services they use. They are the knowledge-giving, awareness-providing organizations that help to confer sovereignty on the consumer.

Demedicalization/Self-Care

"Demedicalization" is a trend that is challenging the dominance of medical professionals in selected spheres of human life. The trend is supported by well-known critics such as Ivan Illich (1976) who have expressed

the concern that too many social problems and life conditions are being unnecessarily "medicalized."

Over the last several decades, an increasing number of behaviors considered sinful or criminal have come to be considered illnesses (Coe, 1978; Fox, 1968 and 1977; Freidson, 1970; Mechanic, 1973; Pitts, 1968; Twaddle, 1973; Zola, 1975). Alcoholism and mental disorders, for example, have been removed from the categories of sin or crime and are now labeled illnesses. Some have even begun to call child abuse a "disease." Similarly, life events such as birth and death now almost always entail a considerable degree of medical intervention.

Many have begun to react to the excesses of medicalization and have urged that certain conditions and life events be demedicalized. One example is pregnancy and childbirth. Some urge that pregnancy be removed from the category of illness and that childbirth be supervised by a midwife rather than a physician. Another example is death (Blauner, 1966; Buckingham, et al., 1976; Kalish, 1965; Kron, 1976). "Death with dignity" is the phrase being used for allowing the terminally ill to die at home rather than in a hospital wired to the latest array of monitoring devices.

Implicit in the argument for demedicalization is the assumption that individuals can and should take greater responsibility for their own health and medical care. In many ways, demedicalization is an extension of the self-help movement to the fields of health and medical care. In some quarters, the demedicalization trend is referred to as the self-care movement. The movement goes beyond the keep-fit, watch-your-weight, stop-smoking, and drink-less campaigns of the recent past. The self-care movement encourages

people to administer their own treatment for minor health problems and to avert potential complications arising from chronic health conditions.

The movement for independent living is very much a partisan in the medicalization/self-care debate. At issue for the movement for independent living is the extent to which the management of disability should remain under the aegis of the medical care system once medical stability has been substantially obtained. Today, most public policy with respect to disability requires some type of professional medical presence, whether that be in the acute stages of disability, in the determiniation of eligibility for income maintenance benefits, or in long-term institutional care. The movement for independent living asserts that much of this medical presence is both unnecessary and counterproductive.

Central to the goals of the movement for independent living is the belief that the management of medically stabilized disabilities should be demedicalized. Disabled persons are insisting that the management of their disabilities is primarily a personal matter and only secondarily a medical matter. A constant medical presence in the lives of disabled persons is said to entail behaviors on the part of both medical practitioners and disabled "patients" that induce dependency and thus are in conflict with rehabilitation and independent living goals.

The Medical Model

To understand how these behaviors arise, it is helpful to turn to the concept of the "medical model," a loosely used concept that often varies with the context in which it is discussed.[18] As used here, the medical

[18]The term, "medical model," is used in at least two ways: (1) as a set of criteria to determine whether a particular form of social deviance should be defined as a "medical problem" (Veatch, 1973), (cont. next page)

model consists of the following assumptions and role expectations in the provision of medical care:

- The physician is the technically competent expert.
- Medical care should be administered through a chain of authority wherein the physician is the principal decision maker, i.e., accountability for the care of the patient is centered on the attending physician.
- The "patient" is expected to assume the "sick role" that requires him/her to cooperate with the medical practitioners caring for him/her.
- The main purpose of medicine is the provision of acute/restorative care.
- Illness is muted primarily through the use of clinical procedures such as surgery, drug therapy, and the "laying on of hands."
- Illness can only be diagnosed, certified, and treated by trained practitioners.

Like most models, this version of the medical model is a rather rigid construction of what is supposed to exist and happen in the provision of medical care. The model does not attempt to be exhaustive; it focuses primarily on those elements that can also help us understand what the demedicalization of disability is all about.

Before evaluating the role expectations of the medical model, it is worth noting some of the model's other features that have been unpalatable to the movement for independent living. One important reason for demedicalizing disability, the movement implicitly argues, is that many of the

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(18 cont.) and (2) as a set of assumptions and behavioral expectations considered typical or normative in the provision of medical care. The second use of the term is the one employed here.

The concept of the medical model is strangely absent from much of the medical sociology literature. The concept is more often discussed in the psychiatry literature (e.g., Siegler and Osmond, 1974), in part because psychiatry operates at the boundaries of medicine where it is not always clear whether a form of social deviance or mental aberration should be labeled a medical problem.

assumptions of the medical model do not fit or apply to the needs of disabled persons. For example, the model's emphasis on acute/restorative care is not in keeping with the needs of long-term disabled persons well beyond the acute phase.[19] Likewise, once beyond the acute phase and living independently, disabled persons are not in need of surgery, drugs, or the laying on of hands that characterizes clinical medicine. Moreover, experienced disabled persons are often not in need of the diagnostic, certification, or treatment services of medical professionals since disabled persons often develop sufficient familiarity with the idiosyncracies of their own condition that they are able to do much of their own medical monitoring and treatment.

The Sick Role

The movement for independent living has been particularly critical of the behavioral expectations of the medical model as defined in the sick role. The sick role in this context has a very specific meaning. The concept of the sick role, as originally formulated by Talcot Parsons (1951: 428-79), is considered the single most important concept in medical sociology. By understanding the requirements of the sick role we can gain a better insight into the position advocated by the movement for independent living.

The sick role consists of two interrelated sets of exemptions and obligations:

- A sick person is exempted from "normal" social activities and responsibilities depending on the nature and severity of the illness.

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[19] Working with chronically disabled patients who have little or noe hope for full recovery (in the conventional sense) is considered by most medical practitioners to be less glamorous and less rewarding than the heroic life-saving and health-restoration activities involved in acute care.

- A sick person is exempted from any responsibility for his/her illness. He/she is not morally accountable for his/her condition and is not expected to become better by sheer will.

These exemptions are granted conditionally. In exchange:

- A sick person is obligated to define the state of being sick as aberrant and undesirable, and to do everything possible to facilitate his/her recovery.

- A sick person is obligated to seek technically competent help and to cooperate with the physician in getting well.

The sick role is intended to be a temporary one. But for the long-term or permanently disabled person there is no immediate recovery in the sense of being restored to one's original physical condition. Because the disability is often an irrevocable part of his/her existence, the disabled person, as a result of the sick role, begins to accept not only his/her condition but also his/her own very personhood as "aberrant" and "undesireable." Moreover, he/she begins to accept the dependency prescribed under the sick role as normative for the duration of his/her disability. Thus, the sick role removes from the disabled person the obligation to take charge of his/her own affairs.

The Impaired Role

This critique of the sick role is affirmed in the concept of the "impaired role" articulated by Gordon (1966) and by Siegler and Osmond (1973). The impaired role is ascribed to an individual whose condition is not likely to improve and who is unable to meet the first requirement of the sick role, the duty to try to get well as soon as possible.[20] Occupants of the impaired

[20]Others (Kassebaum and Baumann, 1965; Safilios-Rothchild, 1970; Segall, 1976; Twaddle, 1969) have also acknowledged the limitations of the sick role as a theoretical construct and have suggested the need to develop alternatives to the sick role concept for the patient/person with a chronic illness or disability.

role have abandoned the idea of recovery altogether and have come to accept their condition and dependency as permanent. In the words of Siegler and Osmond (1973: 56), the impaired role "carries with it a loss of full human status:"

> ...the impaired role does not require the exertions of cooperating with medical treatment and trying to regain one's health, but the price of this idleness is a kind of second class citizenship.

The impaired role is not a normative one or one prescribed by the medical model, but is a role a disabled person is allowed to slip into as the passage of time weakens the assumptions of the sick role.

The impaired role is fictionalized in Thomas Mann's (1927) Nobel Prize-winning The Magic Mountain, a novel about patients living at the Berghof, an international tuberculosis sanitorium for the well-to-do. Here patients abandon the sick role for the impaired role. Siegler and Osmond's (1973: 53) description of the impaired role at the Berghof is informative:

> The impaired role has a lower status than the sick role, but life at the Berghof is so luxurious for these wealthy patients that they do not care. It is true that no one takes them seriously, and their life is ordered for them by the resident physicians, but in return for this child-like status, they are allowed to spend their days as children do, playing card games, taking up hobbies, having meals served to them, "playing" with each other, or, most often, doing nothing at all.

Mann's fictionalized account of the Berghof presents us with one variant of the impaired role as it is found in a particular institutional setting. His account provides us a glimpse of the tendencies toward child-like dependency inherent in the impaired role.

The movement for independent living rejects the behavioral expectations created by both the sick role and its derivative, the impaired role, by

saying that the disabled do not want to be relieved of their familial, occupational, and civic responsibilities in exchange for a childlike dependency. In fact, this "relief" is considered tantamount to denying the disabled their right to participate in the life of the community and their right to full personhood.[21]

Deinstitutionalization/Mainstreaming/Normalization

The dependency creating features of the medical model and the impaired role are most pronounced in institutional settings. Institutions are self-contained social systems that allow house staff and various practitioners to exercise a substantial measure of social control with little outside interference.

Prolonged institutionalization is known to have harmful effects (Corcoran, 1978: 63):

> Patients are encouraged to follow instructions, rules and regulations. Compliance is highly valued, and individualistic behavior is discouraged. The "good" patient is the individual who respectfully follows instructions and does not disagree with staff. On the other hand, the patient who constantly asks for a dime for the pay phone, a postage stamp, or a pass to leave the institution on personal business, tends to be treated as a nuisance or labeled "manipulative." Patients do not make their own appointments, keep their own medical charts, or take their own medications. Responsibility for these things is legally vested in the institution. Yet on the day of discharge, the patient is expected suddenly to assume control of his own health care and life decision making.

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[21] Safilios-Rothchild (1970: 73-81) has proposed the concept of a "disabled role" or a "rehabilitatant role." This role requires the individual to resume "normal" social roles within the limits of his/her physical impairment. As Sifilios-Rothchild (1970: 80-81) suggests, the rehabilitant role is an ideal social role often undermined by the rules and regulations present in the institutional environment in which rehabilitation is supposed to take place.

The trend to deinstitutionalize is one that cuts across many disabling conditions. The best known deinstitutionalization effort is the community mental health movement which has allowed many individuals---often with the use of psychotropic drugs---to leave institutional confinement or remain in the community. Similar examples can be found in other areas such as geriatric care and juvenile corrections.

The deinstitutionalization movement has been backed by the political argument that institutional care is expensive and that community care will save taxpayer money. Proof of this argument has been hard to establish, especially when studies overlook the ever present tendency of institutions to increase utilization to meet capacity.

Severely physically disabled persons and their advocates are latecomers to the deinstitutionalization thrust. This is understandable. Unlike mentally impaired persons or exoffenders, their disability is more difficult to conceal. Moreover, the deinstitutionalization of the severely physically impaired requires substantial environmental or architectural modifications not required by others.

The movement for independent living has adopted many of the same money-saving arguments for deinstitutionalization used by other groups. The only problem is that many of these arguments are beginning to wear thin with representatives of the taxpaying public who have not witnessed any significant decrease in human service expenditures. As latecomers to the deinstitutionalization thrust, severely physically disabled persons are less likely to benefit from the money-saving argument. Public cynicism about deinstitutionalization may prove to be yet another barrier to independent living.

Closely related to the deinstitutionalization movement are the concepts of normalization and mainstreaming. These two concepts have been discussed mainly in connection with developmentally disabled children and young adults. At one time it was thought that the interests of disabled children were best served by confining them to institutions or segregating them into special education classes. Now, the thinking is that a disabled child or young adult becomes more "normal" when "mainstreamed" with his/her able-bodied counterpart. However, normalization goes beyond mere deinstitutionalization. According to Dybwad (1973: 57), it assumes that:

> normal on our earth is trouble and strife, trial and tribulation and the handicapped person has the right to be exposed to it. Normalization...includes the dignity of risk....

Hence normalization takes deinstitutionalization one step further to include the possibility of failure---a fact which the deinstitutionalization movement has not always been prepared to accept.

The dignity of risk is what the movement for independent living is all about. Without the possibility of failure, the disabled person is said to lack true independence and the mark of one's humanity---the right to choose for good and evil.

Common Properties

We have argued that the movement for independent living represents the convergence of several contemporary social movements or trends. The movement for independent living is like a chemical solution consisting of different but compatible and mutually reinforcing elements. Our analysis here has attempted to distill the solution down to its component elements to better understand the social chemistry that makes up the movement for independent living.

However, our analysis can be taken a couple of steps further. We can also understand the movement for independent living by examining the properties common to the movements we have discussed. These common properties or denominators provide us the clues to the movement for independent living's basic ideological commitments. These commitments are the focus of the section that follows.

V

Commitment to a Free Market-Pluralist Ideology

Cutting across all of the major movements we have discussed are three major assumptions or propositions that apply in a special way to the movement for independent living:

- Consumer sovereignty---disabled persons (consumers), not professionals, are the best judges of their own interests; they should ultimately determine how services are organized on their behalf.
- Self-reliance---disabled persons must rely primarily on their own resources and ingenuity to acquire the rights and benefits to which they are entitled.
- Political and economic rights---disabled persons are entitled to freely pursue their interests in various political and economic arenas.

These three common assumptions reveal a great deal about the movement's ideological commitments.

There is a certain danger in reducing complex social phenomena to a few key assumptions or propositions. My purpose here is not to oversimplify but to fashion an argument that seeks to show that the movement for independent living is, with some exceptions, very much committed to a larger

free market-pluralist ideology that has dominated American political life and social policy. Contrary to what some may think, the movement for independent living is not all that radical when its basic ideological commitments are exposed. The movement's commitment to America's political and economic institutions is very much intact.

The three assumptions or propositions we have identified above are also central to the free market-pluralist ideology. The themes of consumer sovereignty, self-reliance, and the right to pursue one's particular interest are immediately evident when we dissect this ideology into its component parts: (1) the economic theory of the free market, and (2) the political theory of democratic pluralism.

Free Market Theory

Free market theory begins with certain assumptions about the nature of humans and their relationship to the larger society. It assumes that people are basically selfish, acquisitive, and act primarily in their own self-interest. Such self-interest is said to be rational: each individual seeks to maximize pleasure and minimize pain. This utilitarian principle is the cornerstone of modern consumer demand theory.[22] No value judgement can be made about the validity of each person's interest. Each consumer is sovereign, that is, each person is the best judge of his or her own interests; individual utility is a personal matter. The satisfaction which one individual receives cannot be compared to that received by a second individual. In other words, interpersonal utility comparisons are not possible.

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[22]In the parlance of neoclassical economic theory, "man" is a utility maximizer: given a choice between two commodities, A and B, an individual will choose those quantities of A and B that will maximize "his" utility subject to the constraint of "his" income.

Individual self-interest is also the basis for determining societal well-being. Each person advances the community's interest by pursuing his or her own interests. Put the other way around, the community's well-being is seen as the aggregation of individual well-being.

Perfect Competition

Individual self-interest is translated into aggregate social well-being through the vehicle of the competitive market. A market is said to be competitive when certain criteria are met. If all are met, then the market is considered to be "perfectly competitive." The criteria for a perfectly competitive market are: (1) rational self-interest, (2) perfect knowledge by buyers and sellers of all present and future market conditions, (3) open access---ease of entry and exit into the market, (4) smallness---no buyer or seller sufficiently large to affect the price, and (5) undifferentiated products.

Of course, these assumptions and conditions are never fully attained in the real world. Nonetheless, to the extent to which they are partially attained, it is felt that a sufficiently competitive situation exists in which individual self-interest is, over time, translated into aggregate social well-being.[23]

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[23]In cases where the criteria are severely violated, such as monopoly and oligopoly, it is usually held that these instances are isolated or are necessary to the "public interest" as in the case of public utilities. Although monopoly, ologopoly, and other market models require that the assumptions of perfect competition be relaxed, these models or modifications do not pose a fundamental threat to neoclassical theory since all the tools of marginal analysis---that are so central to the methodology of contemporary economics---are still applicable.

Additional adjustments have been made to the perfect competition model in the theory of countervailing power. According to this theory, large and highly structured industries are not a matter of special concern because "...private economic power begets the countervailing power of those who are subjected to it" (Gailbraith, 1956: 4). Countervailing (cont. next page)

The perfectly competitive market remains the strictest construction of the free market theory and the analytic point of departure. Perfect competition is not only normative for economic theory but also for political theory. Perfect competition has its political analogue in the theory of "democratic pluralism" or "interest group liberalism" where nearly identical assumptions obtain.

Democratic Pluralism

According to the pluralist theory, the American political process is one in which competing interests organize into groups to rationally pursue their own interests by bargaining in the political market place. The market is governed by certain rules or "a procedural consensus."

The rules of the political market constitute the assumptions of the pluralist model. One of the rules is that there be freedom of entry and exit into the political market place. The open access assumption requires that there be no single group capable of denying other groups their right to participate in the political process. In the pluralist model, power and control are sufficiently distributed to prevent any group from becoming dominant, an assumption closely related to the premise in perfect competition that no buyer or seller is sufficiently large to affect the price. When one group seeks to advance its position by forming coalitions with other groups, countervailing coalitions or forces are likely to develop.

(23 cont.) powers tend to neutralize each other. Strong labor unions neutralize the power of oligopolistic industries; organized buyers neutralize powerful sellers.

> The result, then, is a kind of market equilibrium or invisible hand that harmonizes the interests of all. The harmonious whole is now simply made up of a few neutralized giants rather than numerous atomistically competitive small firms (Hunt, 1972:156-157).

The countervailing power theory demonstrates the adjustments free market apologists have made to preserve their perception of reality.

Bargaining is to the political process what bidding is to the economic market. Because no group is sufficiently dominant in the bargaining process, the various parties must compromise. By moving to some compromise the system tends over time to be Pareto-optimal: it will tend to make some groups better off without making others worse off. Pareto-optimality is not a second-best solution but the optimal solution. It constitutes the point of equilibrium---the point at which political and social harmony is achieved. Equilibrium is the embodiment of the public interest.

In the pluralist system, the oscillations around a given issue are fairly narrow, always tending toward equilibrium. Changes are seldom drastic but tend to be incremental or marginal. Such a system is said to be self-regulating and inherently stable. The automatic and mechanistic character of both perfect competition and pluralism led Lowi (1969:47) to conclude that the "hidden hand of capitalistic ideology could clasp the hidden hand of pluralism, and the two could shake affirmatively."

Applications to Movement for Independent Living

At first blush, some may find it difficult to view the movement for independent living as an apologist for a free market-pluralist ideology. After all, many disabled persons are hardly in the mainstream of this nation's economic and political system. They have been excluded. They can hardly be expected to be apologists for a system that has excluded them.

But this is to miss the point. While disabled persons have been excluded from full participation in the American economic-political system, they still subscribe to the system's most cherished values and assumptions. They still want to become a part of the system.

Take, for example, our frequently cited doctrine of consumer sovereignty. This doctrine embraces the rational self-interest and perfect knowledge assumptions of the perfectly competitive market and asserts that it is the consumer, and not the provider, who should ultimately determine what goods and services should be provided in a free market system. Consumer sovereignty, sometimes referred to as "consumer involvement," is now a fixture within the movement for independent living. The doctrine asserts clearly that because disabled persons are the best judges of their own interests, they should have the larger voice in determining what services are provided in the disability services market.

The search for alternative service delivery systems also reflects the movement's commitment to important free market values. The development of new independent living service centers has sometimes been justified as a way of making the delivery of human services more competitive. The establishment of nonprofit consumer-directed service organizations is said to help break the monopolistic stranglehold of state-controlled human service organizations such as public welfare departments or vocational rehabilitation agencies. Such rhetoric speaks to the open access and smallness assumptions of the perfectly competitive market.

In like manner, the movement for independent living subscribes to the assumptions of the pluralist theory by seeking full access to the political arena. In this case, the political arena is not a formal legislative body, but the constellation of supporting and competing interest groups that

help to shape disability policy---providers, professionals, disability organizations,[24] legislative committees, and executive agencies.

Risks and Dangers

By linking some of the movement's basic assumptions to a larger ideological commitment, we are in a better position to identify and evaluate some of the risks or dangers facing the movement for independent living.

One danger is that the movement for independent living may underestimate the role of economic power in the political arena. Pluralism ignores the economic basis of the political process. It assumes that the political arena is economically neutral. It is not. Those who come to the political market place with disproportionate economic power usually have at their command the intellectual and political dexterity with which to maintain, if not extend, those advantages.[25] As a consumer-based movement with relatively few economic resources, the movement for independent living is not always able to participate in the arena on an equal footing.

Another danger is that by becoming a part of the political process the movement may become more conservative. A pluralist system that oscillates within a few degrees of the point of equilibrium is not likely to tolerate large fluctuations in political thought or ideology. Those already in the system have a vested interest in making sure that the equilibrium is not upset and that pre-existing power relationships are not disturbed.

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[24]By disability organizations I mean groups such as the Easter Seal Society, Muscular Dystrophy Association, the National Multiple Sclerosis Society, the National Paraplegia Foundation, Paralyzed Veterans of America, and other groups representing one or more disabling conditions.

[25]As Schattschneider (1975:34-35) once said: "The flaw in the pluralist heaven is that the heavenly chorus sings with a strong upper-class accent."

Expressed another way, the free-market pluralist ideology suffers from a basic inconsistency in its assumptions: the open access and rational self-interest assumptions are often mutually exclusive. It is always in the interest of incumbent groups to prevent incipient competitors from entering the market. This tendency is to some degree present in the movement for independent living. It seeks services and benefits mainly for the core disability groups represented in the movement. It often sees other disability groups such as the disabled elderly as competitors. Galper (1975:37) speaks to the dangers in such a point of view:

> If we achieve our successes in a competitive relationship with others, we will need to be on guard against them for fear that they'll try to take our gains from us....We will necessarily assume a guarded and uncomplimentary view of others that is destructive to the achievement of important human values, namely community, human warmth, and social integration.

It is to these tendencies that the movement for independent living must be on guard.

Mitigating Features

Fortunately, there are other features of the movement for independent living that will help mitigate some of the more destructive features of the free market-pluralist ideology.

First, the movement has steered away from destructive individualism. It has encouraged community support and mutual responsibility. The emphasis on self-help and self-reliance has a communal as well as an individual component.

Second, the movement has helped to foster a sense of self-worth that cannot always be obtained in the competitive market. In the competitive market, one's labor is often reduced to a commodity to be bought and sold

like other means of production. The competitive market often becomes the standard by which individuals measure their own self-worth. Because the competitive market has often excluded disabled persons, the movement has discounted the competitive market as the sole standard of self-worth. Instead, the movement has worked hard to promote self-esteem through community action and support.

Third, the movement has insisted that the pathology is in the environment, not the individual. In the free market-pluralist conception, the problem is defined as a failure of self-reliance. The movement argues, for example, that the failure to be gainfully employed does not necessarily rest with the individual but with the market which has been unable to make useful work available or accessible.

And fourth, the movement has, in some instances, turned away from the destructive competition that has often characterized disability politics in the past. The movement has been instrumental in the development of new coalitions such as the American Coalition of Citizens with Disabilities (ACCD).

The hidden hand of the free market-pluralist ideology has a remarkably seductive quality. As the movement for independent living becomes more established and recognized there will be the temptation to incorporate more of the values and assumptions that comprise the free market-pluralist frame of reference.

VI

Expression in Disability Services

How have the movement's values and assumptions---as reflected in its relationship to other movements and in its ideology---come to expression in services rendered on behalf of disabled persons? Does our description of the movement's values and assumptions have substance in the form of policy or services? Are there services or policies that we can point to as illustrative of the movement's philosophy?

We have already pointed to some changes in the nation's disability policy that have emerged from the movement's growing influence. The non-discrimination provisions of the 1973 Rehabilitation Act are cases in point. But I would like to go further to illustrate in greater detail how specific services reflect the movement's philosophy. Examples from service delivery should provide us with some tangible evidence as to what the movement for independent living is all about.

Movement Services

Six specific services have become closely associated with the movement for independent living. First are advocacy services that attempt to acquire for disabled persons various rights and entitlements. Second is "peer counseling" intended to foster more assertive behavior in an unaccommodating social and economic environment. Third are attendant care services that assist disabled persons in personal hygiene and housekeeping activities.

Fourth is the removal of architectural barriers. Fifth is adapted housing. And sixth is adapted transportation.[26, 27]

The movement's philosophy not only affects what services are to be provided but also how services are to be provided. It is not important that we consider how each service is rendered. Since my purpose is to be illustrative, I will use the example of attendant care to demonstrate how the provision of this service reflects some of the movement's most cherished values.

Attendant Care

Attendant care is a form of in-home care required by a disabled person who needs assistance from another person with personal hygiene (bathing, dressing, grooming, bowel and bladder care, etc.) and housekeeping. A disabled person may need as much as four to five hours of in-home care per day.

The movement for independent living has actively promoted the attendant care concept because it places the disabled person in control of his/her own care. The disabled person directs his/her own care by recruiting, training, supervising, paying, and if necessary, firing his/her own attendant.

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[26]In many respects, "service" is a misnomer. Instead, the movement for independent living defines the problem to be one of "barriers." The denial of rights and entitlements is a barrier. Inadequate personal care is a barrier. Unadapted housing is a barrier. When the problem is defined in terms of barriers, the goal of independent living is always kept in mind. When the problem is defined in terms of services---or the lack of services---the goal can easily be displaced. All too often, the provision of services becomes an end in itself rather than a means to an end.

[27]Another noteworthy observation about services and barriers is something we alluded to earlier, namely that the problem is assumed to be external to the disabled person. Such a perspective affirms the integrity of the individual and stresses the need for society to make the adjustments needed to allow a disabled person to achieve their due measure of self-fulfillment.

Funds for attendant care are usually provided from public sources[28] to the consumer who in turn pays his/her own attendant. Allowing a severely disabled person to acquire control over something as intimate as his/her own personal care is seen as a major step toward self-determination and independence. The attendant care concept is said to illustrate why physical dependence does not automatically translate into social dependence.

Attendant care can be contrasted with two other main sources of in-home care: (1) care provided by a relative such as a parent or spouse, or (2) care provided by an agency-furnished homemaker-home health aide. The movement's promotion of the attendant care concept is, in part, a response to the dependency that is fostered when care is provided by a relative or by a homemaker-home health aide. For example, a parent caring for an adult disabled child may unintentionally prolong the natural dependency of the parent-child relationship well beyond adolescence.

Likewise, a homemaker-home health aide may unwittingly promote many of the dependency-inducing features cited in our earlier discussion on demedicalization. A homemaker-home health aide is usually recruited, trained, and supervised by a home health agency such as a Visiting Nurse Association agency. Services are usually paid for with Medicare or Medicaid funds. In this service arrangement nearly all the assumptions of the medical model are evident: the homemaker-home health aide is supervised by a registered nurse according to a physician's plan of treatment. The disabled person is expected to assume the patient or sick role. Home health assistance

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[28]The two most common public sources of funding are the federal Title XIX (Medicaid) and Title XX (social services) programs authorized under the Social Security Act.

is usually temporary, the implied assumption being that the condition is an acute one and that the purpose of care is restorative rather than maintenance.[29]

Attendant care is looked to as conventional home health care's demedicalized counterpart. It substitutes self-care and self-reliance for professional supervision.

The attendant care concept picks up on several other important independent living themes. In some quarters, attendant care is more than a service; it is considered a right because it is a survival need. Attendant care has often been promoted as a way of fostering deinstitutionalization. It allows relatively low-skilled individuals to provide personal care in a community setting that would otherwise be provided in an institutional setting. Attendant care is often arranged through self-help organizations, such as centers for independent living, that sometimes serve as financial intermediaries between public agencies and consumers.[30] Even with public financing it is the disabled consumer who is chiefly responsible for arranging his/her own care.

The provision of attendant care also mirrors some free market concepts introduced earlier. The disabled person is expected to freely hire his/her attendant from among those willing to provide such a service. No certification or licensing requirement is made to prevent would-be attendants from

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[29]The medical model is deeply imbedded in the home health regulations under Medicare and Medicaid (DeJong, 1977b:34-38; HEW, 1976:37-40). Consider the Medicare requirements for home health services: the three-day prior hospitalization requirement, the condition-relatedness requirement (home health services can only be provided for the same condition for which the patient was hospitalized), the physician plan of treatment requirement, the skilled nursing requirement, the 100-visit limitation, and others. All of these requirements can be traced to the assumptions of the medical model discussed earlier in this monograph.

[30]In Massachusetts, public funds for attendant care are channeled by public agencies through centers of independent living to disabled users of attendant care.

entering the market. Nor must a disabled consumer choose care providers from a monopolized state-regulated agency. In other words, the attendant care market is largely deregulated. The disabled consumer is sovereign. The role of government is mainly that of a financial intermediary.

In many ways, attendant care is a prototype independent living service. Understanding the nature of this service and the circumstances under which it is provided offers us an empirical basis for understanding much of the movement's philosophy.

VII

Independent Living as an Analytic Paradigm

Independent living is more than a social movement seeking new rights and entitlements for disabled persons. It is also reshaping the manner in which the problem of disability is defined and is encouraging the development of new interventions. What we are witnessing in American disability policy is the emergence of a new "paradigm" that is beginning to redirect the thinking of disability professionals and researchers alike.

Kuhn's Conception of Paradigm

My use of the word paradigm is borrowed from Kuhn's (1970) oft-cited work, The Structure of Scientific Revolutions. As a historian of the natural sciences, Kuhn observed that scientific facts did not emerge by simple accumulation or evolution, but were the products of new ways of thinking---new scientific paradigms. Paradigms define reality for the scientist. They provide the framework by which problems are identified and solved. A paradigm also prescribes the technology needed to solve a given problem.

Kuhn's historical frame of reference is not only applicable to the natural sciences but is appropriate to the social sciences and social policy as well. The concept of a paradigm can be useful here in helping to understand the debate that has been precipitated by the movement for independent living.

Two other concepts are important in Kuhn's analytic frame of reference. The first is the concept of an anomaly---an event or observation that cannot be adequately explained by the dominant paradigm of the times. When a sufficient number of anomalies appear, a crisis is precipitated and disaffected individuals begin to search for an alternative explanation or paradigm. The second is the concept of paradigm shift---when one paradigm is discarded for another. Anomalies do not automatically cause individuals to renounce one paradigm for another. A paradigm shift does not occur unless there is a new paradigm to replace the old. "(A) scientific theory is declared invalid only if an alternate candidate is available to take its place" (Kuhn, 1970:77). Both of these concepts are useful to our inquiry here.

The Rehabilitation Paradigm

The dominant paradigm in disability policy today is the rehabilitation paradigm. The rehabilitation paradigm is evident in both medical and vocational rehabilitation. It could be argued that there are sufficient differences between medical and vocational rehabilitation to speak of two paradigms but there are also a sufficient number of similarities to consider them as one. Since my main interest here is to contrast rehabilitation and independent living as paradigms, the differences between medical and vocational rehabilitation are less important.

In the rehabilitation paradigm, problems are generally defined in terms of inadequate performance in activities of daily living[31] or in terms of inadequate preparation for gainful employment. In both instances, the problem is assumed to reside in the individual. It is the individual that needs to be changed. To overcome his/her problem, the disabled individual is expected to yield to the advise and instruction of a physician, physical therapist, occupational therapist, or a vocational rehabilitation counselor.[32] The disabled individual is expected to assume the role of "patient" or "client." While the goal of the rehabilitation process is maximum physical functioning or gainful employment, success in rehabilitation is to a large degree determined by whether the patient or client complied with the prescribed therapeutic regime.

Severely Disabled Person as an Anomaly

In recent years anomalies have appeared that cannot be explained by the rehabilitation paradigm. The most important anomaly was the fact that very severely physically disabled persons were achieving independence without the benefit of, or in spite of, professional rehabilitation. The irony was that those who needed professional rehabilitation services the most were often succeeding without these services. In fact, some were considered

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[31]Activities of daily living (ADL) is an expression frequently used in medical rehabilitation to refer to everyday activities of bathing, dressing, grooming, eating, drinking, and other basic survival skills. One of the main goals of physical and occupational therapy is to teach patients to become physically less dependent in activities of daily living.

[32]Vocational counseling usually accepts a person's physical disability as a given. At the core of the vocational counseling methodology is a preoccupation with intrapersonal factors thought to be important for job readiness: lack of self-esteem, poor motivation, inadequate personality development, and other psycho-social concerns.

too disabled to significantly benefit from rehabilitation services.[33] It became evident that cooperation with professional rehabilitation was not a prerequisite for independent living. As a result, an increasing number of individuals, particularly among the most severely disabled, have become disaffected and have sought an alternative paradigm.

The Independent Living Paradigm

The independent living paradigm has emerged, in part, as a response to the anomaly of the severely physically disabled person. According to the independent living paradigm the problem does not reside in the individual but often in the solution offered by the rehabilitation paradigm--- the dependency inducing features of the physician-patient or professional-client relationship. Rehabilitation is seen as part of the problem, not the solution. The locus of the problem is not the individual but the environment that includes not only the rehabilitation process but also the physical environment and the social control mechanisms in society-at-large. To cope with these environmental barriers, the disabled person must shed the patient or client role for the consumer role. Advocacy, peer counseling, self-help, consumer control and barrier removal are the trademarks of the independent living paradigm (see Table 3).

The independent living paradigm is now well beyond the embryonic stage of development but the rehabilitation paradigm remains strong. We can expect

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[33]Within medical rehabilitation, it was assumed that a severely disabled patient would, upon discharge, be entrusted to the care of a near relative or be placed in a long-term care facility. Living by oneself in a community setting was not considered a realistic discharge goal. Within vocational rehabilitation, it was assumed that a severely disabled client would, upon case termination, be unemployed or be assigned to a sheltered workshop experience. In both medical and vocational rehabilitation, independent living goals such as living by oneself or becoming gainfully employed were unthinkable.

Table 3

A Comparison of the Rehabilitation and Independent Living Paradigms

Item	Rehabilitation Paradigm	Independent Living Paradigm
Definition of problem	Physical impairment/ lack of vocational skill	Dependence on professionals, relatives, etc.
Locus of problem	In individual	In environment; in the rehab process
Solution to problem	Professional intervention by physician, physical therapist, occupational therapist, voc rehab counselor, etc.	Peer counseling advocacy self-help consumer control removal of barriers
Social role	Patient/client	Consumer
Who controls	Professional	Consumer
Desired Outcomes	Maximum ADL Gainful employment	Independent living

the independent living paradigm to strengthen as movement leaders continue to refine its basic principles. In this period of paradigm shift, we see individuals with loyalties to both paradigms. There are some rehabilitation professionals who have introduced independent living concepts within their practice. They have not totally abandoned the rehabilitation paradigm for the independent living paradigm.[34]

[34]This analysis differs somewhat with Kuhn's. He (1970:77) argues that "(t)he decision to reject one paradigm is always simultaneously the decision to accept another...." The analysis here suggests that the shift or transition to another paradigm is not necessarily an abrupt one.

Implications for Disability Research

Paradigms not only define problems and the range of appropriate interventions, they also determine what is relevant for purposes of research. "(T)here is no such thing as research in the absence of any paradigm" (Kuhn, 1970:79). Underlying each paradigm is a theory of causation spelling out the relevant set of dependent and independent variables.

In traditional rehabilitation research, the emphasis has been on outcomes such as gains in "self-care,"[35] mobility, and employment. The intervening variables thought to be critical have generally centered around patient/client characteristics and various kinds of rehabilitation therapies. Patient/client characteristics typically include age, sex, physical impairment, and the psychological make-up of the individual. The inclusion of these characteristics reflects the assumption in rehabilitation research that the problem to be addressed resides in the individual. The issue for rehabilitation research is not whether rehabilitation works, but which therapy or intervention works best for which groups of patients or clients.

Independent living as a paradigm of research has only begun to emerge. Much of the research incorporating independent living concepts has yet to find its way into the published literature. Nonetheless, given the values and assumptions posited by the movement for independent living, we can at least begin to identify some of the variables considered relevant for research.

The theory of causation implicit in the independent living paradigm asserts that environmental barriers are as critical as, if not more so than, personal characteristics in determining disability outcomes. Moreover,

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[35]Self-care, as it is used here, should not be confused with demedicalization or self-help, which is more closely associated with the movement for independent living. Self-care here refers to the ability of an individual to feed, dress, and groom him/herself without the assistance of another person.

the independent living paradigm differs from its rehabilitation counterpart in defining outcome variables relevant for research. While rehabilitation has stressed the importance of self-care, mobility, and employment, independent living has emphasized a larger constellation of relevant outcomes. In addition to the three outcomes[36] considered desirable in rehabilitation, independent living has emphasized the importance of living arrangement, consumer assertiveness, outdoor mobility, and out-of-home activity.

The challenge for disability researchers is to operationalize the concepts introduced by the independent living paradigm. In particular, we need to operationalize both the outcomes and intervening variables deemed important by the independent living paradigm. In terms of outcomes we need to identify and weight a set of variables that are most reflective of independent living values. In terms of intervening environmental barriers we need to define meaningful measures of environmental constraint.

In short, the movement for independent living presents us with a set of hypotheses and propositions that not only need to be operationalized but also empirically tested. My purpose here is to identify some of these hypotheses given the values and assumptions espoused by the movement for independent living. For openers, I would like to suggest the following hypotheses:

- The longer a person's period of hospitalization, the less likely is that person to achieve desired independent living outcomes following discharge. This hypothesis speaks to the demedicalization issue.

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[36]In some instances the independent living paradigm would reject the significance of self-care as an outcome variable. The fact that a disabled person needs more assistance from a human helper does not necessarily imply that he/she is more dependent. If a person can get dressed in 15 minutes with human assistance and then be off for a day of work, that person is more independent than the person who takes two hours to dress and remains homebound.

- The greater the architectural barriers within a person's living or potential working environment, the less likely is a person to achieve desired independent living outcomes.

- The longer a person's prior history of institutionalization, the less likely is a person to achieve desired independent living outcomes.

- The greater a person's unmet personal care or attendant care needs, the less likely is a person to achieve desired independent living outcomes.

- The larger a person's potential loss of public benefits when becoming employed, the less likely is a person to achieve desired independent living outcomes. This hypothesis speaks to the "disincentives" issue.

This is not an exhaustive list of potential hypotheses but does illustrate the research directions proposed by the independent living paradigm.

One might ask whether these hypotheses belabor the obvious. "Ask any disabled person," one might say. While these propositions appear to be intuitively true, we are not certain about the relative importance of each environmental constraint. Nor do we know the collective importance of these environmental variables relative to individual characteristics. We need to go beyond mere statistical significance to show what percent of the variance in outcome can be explained by variables considered important by the independent living paradigm.

Each of the hypotheses we have identified here speaks to a problem or source of difficulty that is external to the individual and can often be traced to a public policy that can be rectified through legislative or administrative action. According to Eggert (1973:51):

> Environmental and individual characteristics...have qualitatively different degrees of potential manipulation. Demographic characteristics such as age, sex, and race cannot be altered. Other individual characteristics, such as degree of independence in Activities of Daily Living (ADL) are subject to slight modification through a program of physical therapy.

> The nature and level of veterans benefits, an environmental variable, is subject to drastic alteration by the stroke of a pen on a piece of federal legislation.

Traditional rehabilitation research that belabors the significance or insignificance of individual patient/client characteristics has little policy relevance---and in many instances, has little clinical relevance as well. As a paradigm of research, independent living offers us an opportunity to steer away from the myopic preoccupation with unalterable individual characteristics that divert our attention from the larger institutional and environmental context in which disabled people live. The institutional and environmental context has for too long been accepted as a given.

VIII

The Future

In a mere seven years the movement for independent living has grown from a small band of disabled persons struggling for simple rights to a significant political force shaping the future of disability policy. With its meteoric rise, can we predict how the movement for independent living is likely to shape the future of disability policy? Can we predict what the movement will look like in another decade? These questions cannot be answered directly. However, we can discern some trends and issues that are likely to influence the future course of the movement and its impact on disability policy.

The Role of the Independent Living Paradigm

The concept of paradigm, introduced in the last section, can be useful in predicting how the movement for independent living is likely to affect

disability policy. Paradigms are more than analytic frames of reference, they also serve important latent social functions. They prepare students, scholars, and practitioners for membership in a particular discipline. They help to define the boundaries of professional practice and help to confer legitimacy upon professional groups.

Up till now the field of disability policy (for physically impaired persons) has been the captive of the rehabilitation paradigm and rehabilitation professionals whose limited frame of reference in many ways narrowed the options available to disabled persons. The emphasis on one-to-one clinical practice often excluded the contributions of other disciplines. By broadening the problem of disability to include a wide variety of environmental variables, the independent living paradigm is opening the field of disability policy to other disciplines. The emphasis on rights and entitlements is encouraging the participation of legal professionals; the matter of architectural barriers is stimulating new interest on the part of architects;[37] and the problem of work disincentives arising from various public assistance programs is sure to invite economists who have plowed similar ground in income transfer programs geared to nondisabled groups.[38] The infusion of new perspectives precipitated by the movement for independent living will undoubtedly invigorate the field of disability policy and move the field beyond its traditional rehabilitation focus.[39]

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[37]One finds an increasing number of architecture-for-the-handicapped courses in professional schools of architecture. While most of these courses are now considered electives, the day may come when instruction in barrier free design will become mandatory.

[38]Economists are involved to a limited degree in rehabilitation research. To date, their contribution has been mainly in the form of cost benefit analyses of vocational rehabilitation programs.

[39]In this regard, it is alarming to note how little vocational rehabilitation counselors understand about the rest of the human (cont. next page)

The Role of Able-Bodied Persons

One of the most vexing issues in the years to come will be the role of able-bodied persons in the movement. In some quarters, there are strong feelings that only disabled "consumers" should hold the majority of leadership positions within the movement.[40] The issue is reminiscent of the civil rights

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(39 cont.) service system with which severely disabled persons must cope in order to live independently. Historically, vocational rehabilitation agencies have existed as separate state agencies or as divisions within state departments of education. It was thought that this independence from the remainder of the human service system would give vocational rehabilitation greater political visibility and shield it from being tarnished by the negative image of state public welfare departments. But the price of this independence has been high. It has resulted in a bureaucratic insularity that deprives vocational rehabilitation counselors from knowing how to effectively utilize the rest of the human service system for the benefit of its clientele.

This insularity is very evident in the work disincentives problem embedded in the Supplemental Security Income (SSI) program and its predecessor, the Aid to the Totally and Permanently Disabled (ATPD) program. These income assistance programs have been administered either by state departments of public welfare or through Social Security Administration district offices. The SSI program, because of its size, has a significant impact on client behavior, especially when eligibility for SSI income benefits also establishes eligibility for a wide variety of other medical and social service benefits. A serious disincentive problem develops when a disabled person returns to work and loses not only his/her SSI benefits but also related medical and social service benefits needed for independent living. Yet, many vocational rehabilitation counselors do not know or understand the elementary rules of SSI eligibility that precipitate the disincentives problem.

The disincentives problem, although it has been around for years, has not become a serious national issue till recently, when independent living leaders helped to introduce H.R. 12972 in the 95th Congress. (See also discussion on pending legislation, page 59.) Ironically, the disincentives problem has been a political issue in the Aid to Families with Dependent Children (AFDC) program since its inception in the 1930's. Yet, rehabilitation professionals have ignored the disincentives problem as a significant disability policy issue even when the magnitude of the disincentive has been considerably greater in the SSI program than in its sister program, AFDC. This issue, I believe, illustrates why the movement for independent living will go a long way in helping to rescue the formation of disability policy from the rehabilitation establishment.

[40]This issue surfaced at the National Conference on Independent Living held in September 1978, in Houston, Texas. There a proposal was made that "Federal funding of independent living service programs should be awarded only to organizations having majority consumer involvement in their decision-making structures and significant representation of the disabled on their staffs." This proposal was perhaps the most divisive made at the conference.

movement when whites were asked to relinquish their leadership roles in black advocacy organizations. The debate on this issue is likely to intensify over the next few years. The issue of consumer involvement will become less controversial as able-bodied persons begin to realize the significant role they have outside movement organizations especially in the development of public policy affecting disabled persons.

Another unresolved issue is the question of who is a "consumer." This question is particularly relevant to parents of disabled children. Parents have often identified themselves as surrogate consumers on behalf of their children. The movement has been somewhat antiparent since parents of disabled children often perpetuate childhood dependency into adult life. The movement has often viewed parents as a major barrier to independent living.

Pending Legislation

At the time of this writing it appears that the 95th Congress will pass legislation (S. 2600 and H.R. 12467) authorizing new funding for independent living under the Rehabilitation Act. This new authorization presents both opportunities and risks for the independent living movement. It will give the movement an opportunity to strengthen existing independent living programs and to extend independent living services to parts of the nation where none exist. It also presents the movement an opportunity to say that independent living has arrived as a credible political movement within the nation. The risk is that new funding could bureaucratize the movement and blunt its cutting edge as it becomes involved in organizational maintenance activities at the expense of advocacy. Moreover, independent living funds may be diverted into activities that are only marginally associated with independent living, thus diluting the meaning of what independent living is all about. Finally,

since new funding will come through the Rehabilitation Act, there is the danger that the movement may become captive of the rehabilitation establishment.

Legislation is also pending in the 95th Congress (H.R. 12972) to remove certain work disincentives for disabled persons supported by the Supplemental Security Income (SSI) program.[41] Disincentives under the SSI program are most serious for severely disabled persons who lose not only their SSI benefits but also their medical and social service benefits when becoming gainfully employed. If passed, H.R. 12972 will also present opportunities and risks. It presents the opportunity for some to become more independent through gainful employment. But the legislation, if not amended, may encourage marginally disabled persons to remain on SSI longer than necessary, thus adding to the cost of the program. One must consider the fact that the number receiving assistance under the SSI program and the Social Security Disability Insurance (SSDI) program has increased dramatically over the last several years. The risk for the movement is that spiraling costs in the SSI and SSDI programs may invite a public backlash against disability programs.

In Closing

The movement for independent living represents a new chapter in American disability policy. Considering its brief history, the movement's accomplishments in legislation, services, and consciousness raising have been truly remarkable. But the movement has only begun. We can expect the movement to reach out to new disability groups and to enlarge its age base as its

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[41]H.R. 12972 was introduced in the House of Representatives in June 1978 by Representative Martha Keys of Kansas. The bill passed the House with a very decisive bi-partisan vote of 399 to 4. The bill is in large part a product of independent living advocates in California. As of this writing, the bill is awaiting action in the Senate where it has yet to be voted out of committee.

initial adherents grow older. We can also expect the movement to produce a growing and sophisticated disability literature as it continues to refine its concepts, programs, and services.

The movement's most significant contribution is that it has given disabled persons a significant voice in their own future and has fostered a new sense of dignity and pride that for too long has been denied the nation's most disabled citizenry. This will continue to be the movement's most important contribution in the years to come.

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